University is all about late nights, drinking and sleeping in – right? Not necessarily. As a young person with epilepsy these may be the last things on your mind, or this may be the lifestyle you are looking for. Whatever your hopes and expectations, making epilepsy just part of your life may help you to get the most out of your experience at university.

University life brings with it new people and new experiences which can be both exciting and scary. Thinking and planning ahead can make the transition to university life smoother, giving you more time to get excited about what’s ahead.

**Living arrangements**

“I’ve been very naughty in the past and I haven’t sort of informed the people I’m living with [laughs]. Which is why it came as the greatest shock to them if something did happen. It took me a very long time to even come out quietly, a casual hint, not sort of coming up to them, greeting hands, “Hello, yes we’re going to be living together, this is my label, I’m an epileptic.”

Zoe, young person with epilepsy

When you go to university, there may be a range of options about where you will live. If you are going to university close to home, you may choose to live at home. Or you may want to move out of home and into student accommodation. If you are moving away to go to university, there may also be a range of accommodation available: you may be able to move into student halls of residence, or a shared house or flat. Or you may live on your own.

It is often worth thinking about what sort of accommodation would suit you best, as well as what you would like.

- Could you live in student halls of residence where there will be a warden available at all times should you need it? Can you stay in halls of residence for your entire course or will you have to move out after the first year?
- Do you need any particular equipment to make your living environment safer? For example, do you need a safety pillow? Do you need a shower rather than a bath, or a microwave rather than an oven to make your meals?
- Do you need help during or after a seizure? If so, who might be able to help you and how will you call for help?
- What help might be available to adapt your living arrangements to make it safer if you have a seizure? For example, would it be possible to have a seizure alarm or call alarm fitted in the room so that you can call for help if you need it?

It may be a good idea to get in touch with the university accommodation office as soon as possible to talk through what options are available, what your needs are and how they can best help you.

**Who should you tell?**

You may already have thought about who you want to tell you have epilepsy. Or you may feel that you don’t want to tell anyone. If your seizures are controlled and you don’t have any, you may feel that there is no need to tell anyone. The choice is really yours, but you may want to think about the following points.
• If you need any support or help, for example from your lecturers or the student disability service, you will need to tell them that you have epilepsy. While they have to help students with disabilities, they can only do this if you talk to them about your epilepsy.

• If you need financial help, such as Disabled Students’ Allowances, you will need to disclose that you have epilepsy in order to qualify. This also applies to other sources of financial help, such as the disabled-persons railcard or other discounted travel.

• If you have seizures, it might be useful for people to know about your epilepsy so that they know what to look out for, and how to help you, during a seizure.

• You might just want to tell the people you spend a lot of time with, who you live with, or who you take classes with.

“I was quite stressed because it was sort of Fresher’s week, it was prompting more seizures, but, that was kind of fine, I can deal with the seizures. It was more having to explain it when you are meeting sort of a hundred people in a day, two hundred people in day, so when to tell people, and it means that some people you meet you’re probably not gonna see again, and so I didn’t want to kind of tell them immediately.”

Anna, young person with epilepsy

It may not be easy to tell someone that you have epilepsy. How do you bring up the subject? When do you tell them – when you first meet or after you know them a bit better? You might have had good or bad experiences of telling people, which can affect how confident you feel about telling other people.

“When do you bring it up? When do you tell them? What point do you tell someone that I have epilepsy? And by doing so, by actually sitting down and telling them are you make too much of a big deal about it? And I think in that way it’s made me very afraid.”

Helen, young person with epilepsy

Planning what you want to say might make you feel more confident and comfortable. You can then tell them how and when you want to on your terms.

“I’ve never felt shy about telling other people. I think what I do get worried about is if I kind of make, I’m worried about making too much of a big deal about it in case people think that I’m fixated on it or anything. So I just try and say enough that people understand what I’m doing, the kind of seizures that I’m likely to have and what they should do about it, and then I don’t need to talk about it again. But I try and to tell people before otherwise they feel awkward or some people can kind of felt left out if I’ve not told them.”

Anna, young person with epilepsy

If you have an iPhone you can download our free app, and use that to explain about your epilepsy. Or you can call us for some first aid cards that you could give out to people, or use the first aid section of this website to show them how they can help you if you have a seizure.

Visit www.epilepsysociety.org.uk/digitalmedia for more information.

Spare time: leisure and sport
Going out and having fun is important to us all. So does your epilepsy have to get in the way? As epilepsy varies from one person to another, what is right for one person may not be right for you. If you know that your epilepsy affects you in a particular way, you can often make your own decisions about what you can do. For example, if your epilepsy makes you very tired, early morning activities might not be for you. If you have seizures without a warning, doing activities with someone who knows about your epilepsy, might make it safer if you have a seizure.
What sports can I do?
Most people with epilepsy can do most sports, but it does depend on how your epilepsy affects you. Playing team sports that involve other people, like football, can carry a risk of head injury if you collide with someone. Sport and leisure activities in and around water, or done at heights, may be risky if you still have seizures. But safety measures can reduce the risks in most cases. See our leisure page for more information.

Be realistic about what you want to do, what the possible risks could be for you, and how you can reduce those risks. For example, have a friend with you who knows what to do if you have a seizure. Telling other people about your epilepsy, like your team coach or a lifeguard at the pool, means they can help you if you have a seizure. Don’t forget that these activities also depend on you as a person: your skills and attributes. Having epilepsy doesn’t have to stop you from becoming a champion tennis player!

TV and computer games
For most people with epilepsy, watching TV and playing computer games won’t cause any problem. A small percentage (about 5%) of people with epilepsy have photosensitive epilepsy. This is when seizures are triggered (set off) by flashing or flickering lights, or by seeing moving patterns like stripes or checks. If you have photosensitive epilepsy, some kinds of flashing images, lights or patterns on computer games could trigger seizures. This depends on what the images are, how close you are to the screen and how dark the room is. Computer games that have flashing images may carry a warning on the packaging. Modern flatscreen computers and TVs either do not flicker at all, or have a flicker rate that is too fast to cause a problem.

Theme parks, festivals or gigs?
Rides at theme parks, noise, loud music, crowds and late nights can get your excitement or stress levels rising, or can be tiring. For some, these situations could trigger a seizure, for other people they won’t. Learning if your epilepsy has any triggers like these can help you make decisions about what you can do.

Making the most of Fresher’s Week
Fresher’s Week is usually the first week of term, before the lectures and work start. It is an exciting time with lots of activities and events that give you the opportunity to meet new people, make friends and try out new activities. You can also sign up for groups and courses that run through the term. But it can also be overwhelming and hectic, with lots going on and crowds of people, and feeling the need to ‘fit in’. Remember that many people will be feeling the same way as you, regardless of having epilepsy (or not).

There are lots of websites set up to help you get the best from Fresher’s week.
- Studentastic (www.studentastic.co.uk) has lots of ideas about how to make Freshers’ week work well, such as breaking the ice with your neighbours, feeling happier with your appearance and being yourself.
- Freshers (www.freshers.co.uk) is a website created to help you prepare for university, and get in contact with other people at your university before terms starts.

Drink and drugs
“I can drink yeah, but I’ve got to put a limit on myself, like I can’t get absolutely up bladdered off my face, but I can have like a good drink and be okay.”

Kirsty, young person with epilepsy

Although students are always labelled as drinking too much and doing drugs, this isn’t student life for everyone. But it may be worth thinking about how you might handle conversations, and opportunities, around drink and drugs. Having a good time when you go out is important. But for some people a party lifestyle can make seizures more likely to happen, if their seizures can be triggered by being tired from late nights, alcohol or drugs.

Alcohol
Drinking alcohol is a personal choice and the effect of alcohol varies from one person to another. Some people find that they are ok to drink, others find that it guarantees a seizure the next day.
“Drinking alcohol can increase the likelihood that I’m gonna have a seizure, so I try not to get really drunk. I try if I’m drinking to make sure that I’ve got all the other things sort of secure. Because if I’m really tired, and I haven’t eaten and then have a drink, I’m really likely to have a seizure. So if I try and kind of organise it more, just make sure that I’m not making it really likely that I’ll have a seizure, then it’s not too bad.”

Anna, young person with epilepsy

It might be useful to find out how many units of alcohol you are drinking and what your limits are. As a general guide 1 unit = a 25ml single measure of spirits, 1/3 of a pint of beer or 2/3 of an ‘alcopop’. But you can check the label to see the strength of what you are drinking. It is usually recommended that people with epilepsy have no more than 1-2 units per day, for the following reasons.

- Drinking alcohol can trigger seizures, often during a hangover (when your brain is dehydrated). Drinking water in between alcoholic drinks can help reduce the chances of a hangover.
- Being sick could affect the level of anti-epileptic drugs in your system, which may affect how well your seizures are controlled.
- Alcohol can disrupt your sleep, which can make seizures more likely if tiredness is a trigger for you.
- Alcohol does not mix well with some anti-epileptic drugs and can make some side effects worse.

The information leaflet that comes with your drugs will normally say if it is best to avoid alcohol.

“I went through a drug stage. The drug stage was, it started off with just smoking a bit of cannabis which then moved on to MDMA, Ecstasy, as some people call it. After a while it did get serious and I was doing it a lot, but then once I realised myself, that it was not only a bad thing, but it was a bad thing especially for me. For example the next morning, you know, there was gonna be a definite risk of me having a seizure.”

Matt, young person with epilepsy

Not every student is waiting to be offered drugs. But you may be thinking about what to do if you are offered them, or have already decide what you will do. Whether you take drugs or not is your personal choice but it might be worth knowing that cannabis, ecstasy, speed, cocaine and other drugs can all increase the chance of having a seizure.

Visit www.talktofrank.com for more information.

Sex and relationships

Many young people will worry about sex and relationships, whether they have epilepsy or not. Getting close to someone else can be great, but it can also leave you feeling vulnerable. If you have epilepsy, you might also be thinking about when to tell your partner, how it will affect your relationship or will they go off you?

“I’d only been with him a month when I was diagnosed and I thought oh no, he’s gonna run away, I’ve got this thing, and he totally understood about it. He talks to me about it with everything, he asks me like how I’m feeling.”

Kirsty, young person with epilepsy

And you might be worried about having a seizure during sex. While this is possible it is probably no more likely than having a seizure at any other time.

“I think that like in general I have seizures the more panicky and under pressure I feel, the more seizures I have. So if I’m panicking then the likelihood goes up. I tend not to be panicking during sex so its fine and that’s the kind of general indicator.”

Finlay, young person with epilepsy

Planning contraception and safe sex is important to protect you and your partner against unwanted pregnancy and sexually transmitted infections (STIs). For girls and young women with epilepsy, there are particular issues around contraception that can affect both seizures and the effectiveness of contraception as some methods of contraception affect and are affected by anti-epileptic drugs.
Risk and safety
Life for people with epilepsy is often a balance between managing epilepsy and doing the things that they want to, to have a ‘normal’ life. The balance is not always easy to get right. Having epilepsy does cause risks, and there are safety issues to consider. But it is also important to keep risks in perspective and to avoid making generalisations about what you ‘can’t do’ just because you have epilepsy.

The key to looking at safety issues and managing risks is to think about:
• what the activity or situation is?
• what the risks associated with this activity or situation are for anyone?
• what is it about your epilepsy or seizures that put you at more risk than other people? and
• how these can risks be reduced?

For example, riding a bike on a busy road can be risky for any cyclist. For someone with well-controlled epilepsy who doesn’t have any seizures, the risk may be no greater. But for someone who has seizures without warning, the risk of injury is greater because they could have a seizure and come off their bike. Cycling on quieter roads or with another person, may help to reduce the risk of injury if a seizure happens.

“Yeah, it does affect it [daily life] it is almost like doing a risk assessment everywhere you go and your whole time you are thinking about the potential possibility of having a seizure and how that is going to cause a problem or affect you at that time or where you are.”

Francesca, young person with epilepsy

How serious can the risks be?
For most people with epilepsy, when seizures happen they last a few seconds or minutes and then they recover and can carry on with normal life. But for some people, there are complications with seizures that can have serious consequences. Although this is a difficult topic to read about, it might be helpful to know about it so that you can make informed decisions about managing your epilepsy and the risks around it.

Status epilepticus or ‘status’ and SUDEP
Usually seizures stop by themselves. When a seizure goes on for a long time without stopping, or repeated seizures happen without the person recovering in between and this goes on for 30 minutes the person is in ‘status’. If status happens in a convulsive seizure (when the person is unconscious and shakes), an ambulance needs to be called. Emergency medication may need to be given to stop the seizure so that it doesn’t cause lasting damage to the brain.

Although it is very rare, it is possible to die due to epilepsy. Sometimes this happens due to sudden unexpected death in epilepsy or ‘SUDEP’. SUDEP is when a person with epilepsy dies suddenly and where no other cause of death is found. It is hard to be sure why SUDEP happens, but it may be that during a seizure the person’s breathing or heartbeat are affected.

“I was angry because I wasn’t told. It was something we picked up in a leaflet and I think people should be informed. I think it does scare people maybe. I’m not sure when is a good time to be told, but it’s something, I think now, people are told about it more now... But yeah, I think people should be told, and they shouldn’t have to find out and it is important to know the risks so that you can prevent them you know.”

Bex, young person with epilepsy

Getting the best seizure control possible is often the best way to reduce risks around epilepsy and seizures.
Living a full life

‘Living a full life’ might feel elusive and impossible to you right now. But trying to find ways to make epilepsy just part of your life might help you to make the most of going to university. The key to achieving a fuller life might be in taking care of yourself, taking control of your epilepsy, planning ahead and making the most of what help and support there is available to you.

If you would like to talk to someone about anything you have read here, you can call our epilepsy helpline on 01494 601 400 (national call rate) from 9am to 4pm, Monday to Friday, Wednesday 9am to 8pm. Or you can talk to people online through our Epilepsy Society forum at www.epilepsysociety.org.uk/forum

Epilepsy Society is grateful to YouthHealthTalk (www.youthhealthtalk.org), and the young people featured on their website, for allowing us to use their quotes.